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NO. 95-1858

THE SUPREME COURT OF THE UNITED STATES

October Term, 1996

Dennis C. Vacco, Attorney General of
the State of New York, et al., Petitioners,
v.
Timothy E. Quill, MD, et al., Respondents,

On Writ of Certiorari to the United States
Court of Appeals for the Second Circuit

NO. 96-110

THE SUPREME COURT OF THE UNITED STATES

October Term, 1996

Washington, et al., Petitioners,
v.
Harold Glucksberg, MD, et al., Respondents,

On Writ of Certiorari to the United States
Court of Appeals for the Ninth Circuit

Brief of Amicus Curiae Choice In Dying, Inc.

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32 pp

TABLE OF CONTENTS

TABLE OF AUTHORITIES

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Lakshmipathi Chelluri et al., Intensive Care for Critically Ill Elderly: Mortality, Costs, and Quality of Life, 155 Archives Internal Med. 1013 (1995). 5
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Harvey Max Chochinov et al., Desire for Death in the Terminally Ill, 152 Am. J. Psychiatry 1185 (1995). 18,22
Nicholas A. Christakis & David A. Asch, Biases in How Physicians Choose to Withdraw Life Support, 342 Lancet 642 (1993). 15
Nicholas A. Christakis & Jose J. Escarce, Survival of Medicare Patients After Enrollment in Hospice Programs, 335 New Eng. J. Med. 172 (1996). 13
Charles S. Cleeland et al., Pain and Its Treatment in Outpatients with Metastatic Cancer, 330 New Eng. J. Med. 592 (1994). 19
Ezekiel J. Emanuel, Cost Savings at the End of Life, 275 JAMA 1907 (1996). 13,19
Ezekiel J. Emanuel et al., Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences of Oncology Patients, Oncologists, and the Public, 347 Lancet 1805 (1996). 4,18
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Ivan Lichter & Esther Hunt, The Last 48 Hours of Life, 6 J. Palliative Care 7 (1990). 15, 17
Robert M. McCann et al., Comfort Care for Terminally Ill Patients. The Appropriate Use of Nutrition and Hydration, 272 JAMA 1263 (1994). 8
Steven H. Miles et al., Advance End-Of-Life Treatment Planning, 156 Archives Internal Med. 1062 (1996). 14
Franklin G. Miller, Legalizing Physician-Assisted Suicide by Judicial Decision: A Critical Appraisal, (April 1996). 10
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Donald J. Murphy et al., The Influence of the Probability of Survival on Patients' Preferences Regarding Cardiopulmonary Resuscitation, 330 New Eng. J. Med. 545 (1994). 6
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Robert A. Pearlman, Variability in Physician Estimates of Survival in Acute Respiratory Failure in Chronic Obstructive Pulmonary Disease, 91 Chest 515 (1987). 13
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David B. Reuben et al., Clinical Symptoms and Length of Survival in Patients with Terminal Cancer, 148 Archives Internal Med. 1586 (1988). 13

INTEREST OF AMICUS CURIAE

Choice In Dying, Inc., ("Choice In Dying") as amicus curiae, takes no position with respect to the holdings in the two cases under review by this Court, nor does it take a position with respect to the legality or constitutionality of physician-assisted suicide. Numerous briefs exploring the constitutional and legal aspects of these cases have been filed with the Court. Choice In Dying does not wish to duplicate the work done by other amici. However, to establish an empirically based framework by which these important issues may be considered, Choice In Dying deems it crucial that the Court also be fully informed about:

(1) the limitations of available empirical evidence concerning physician-assisted suicide;

(2) the important distinction between physician-assisted suicide and other accepted options for end-of-life medical care;

(3) the gap between available technology for managing pain and other symptoms associated with terminal illness and actual physician practices; and

(4) the gap between the availability of effective care for the terminally ill and its accessibility to the general public.

Choice In Dying is in a unique position to provide the Court with this information. It is the oldest and the only national organization devoted solely to a broad range of end-of-life issues. Its mission is to secure the right of patients to make decisions about their end-of-life medical care and to promote quality care of dying patients. The organization's work includes providing a professionally staffed national hotline to re-

spond to the three-to-five thousand people contacting it each month with requests for facts, counseling, consultation and crisis resolution. Choice In Dying also provides public, physician and other professional education, and monitors changes in state and federal legislation related to all end-of-life issues.

Choice In Dying respectfully submits this brief to provide the Court with a synthesis and analysis of empirical evidence available as a result of scholarly study and the organization's unique access to the actual experience of thousands of dying individuals and their surrogates.

JURISDICTIONAL STATEMENT

Amicus curiae takes no position as to any jurisdictional statements contained in the petitioners' or the respondents' briefs.

STATEMENT OF FACTS

Amicus curiae takes no position as to any statements of fact contained in the petitioners' or the respondents' briefs.

POINTS RELIED ON

I.
THERE IS PUBLIC AND PROFESSIONAL CONFUSION ABOUT END-OF-LIFE LEGAL AND MEDICAL ISSUES

A. THERE IS MISINFORMATION AND MISUNDERSTANDING ABOUT LIFE-SUSTAINING TREATMENTS

B. THERE ARE IMPORTANT DISTINCTIONS BETWEEN THE WITHHOLDING OR WITHDRAWAL OF LIFE-SUSTAINING TREATMENT AND PHYSICIAN-ASSISTED SUICIDE

C. IN BOTH CASES UNDER REVIEW, THE SECOND AND NINTH CIRCUIT COURTS HAVE BLURRED THE DISTINCTION BETWEEN PHYSICIAN-ASSISTED SUICIDE AND THE POTENTIAL DOUBLE EFFECT OF PAIN MEDICATION IN CERTAIN CIRCUMSTANCES

D. THERE IS A LACK OF CONSENSUS AS TO THE DEFINITIONS OF TERMINAL ILLNESS

E. INDIVIDUALS' RIGHT TO FORGO TREATMENT IS POORLY UNDERSTOOD BY THE PUBLIC AND INSUFFICIENTLY HONORED BY PROVIDERS

II.
PAIN AND OTHER PHYSICAL SYMPTOMS ASSOCIATED WITH TERMINAL ILLNESS ARE OFTEN NOT ADEQUATELY MANAGED

A. THERE IS OVERUSE OF POTENTIALLY PAINFUL LIFE-SUSTAINING TREATMENT IN DYING PATIENTS

B. DATA SUGGEST THAT DYING WITHOUT LIFE SUPPORT CAN BE A PEACEFUL PROCESS

C. TECHNOLOGY IS AVAILABLE FOR MANAGING PAIN AND OTHER SYMPTOMS ASSOCIATED WITH TERMINAL ILLNESS

D. STATE-OF-THE ART CARE FOR SYMPTOMS ASSOCIATED WITH TERMINAL ILLNESS IS NOT ROUTINELY PROVIDED

E. PUBLIC MISCONCEPTIONS ABOUT MANAGEMENT OF PAIN AND SUFFERING DISTORT DEBATE ABOUT PHYSICIAN-ASSISTED SUICIDE

III.

THE NATIONAL CONTROVERSY CONCERNING PHYSICIAN-ASSISTED SUICIDE IS RELATED TO SERIOUS GAPS IN EMPIRICAL DATA

A. EMPIRICAL DATA ABOUT PHYSICIAN ATTITUDES AND PRACTICES CONCERNING PHYSICIAN-ASSISTED SUICIDE IS LIMITED

B. EMPIRICAL DATA ABOUT PATIENT ATTITUDES AND PRACTICES CONCERNING PHYSICIAN-ASSISTED SUICIDE IS LIMITED

PRELIMINARY STATEMENT

Multiple factors contribute to the current controversy about medical care at the end of life. Among the most significant of these factors is the misapplication of medical technology for dying patients and the potential limitations in access to appropriate care at the end of life. Other factors include developing reform in the way that health care is organized and delivered,[1] evolution in the laws governing health care[2] and changes in the

[1]Ezekiel J. Emanuel, Cost Savings at the End of Life, 275 JAMA 1907, 1912 (1996).

[2]See Cruzan v. Director, Missouri Dept. of Health, 497 U.S. 261 (1990); See also Patient Self-Determination Act, 42 U.S.C. §1395 cc(f) (1)-(3) (1990) (the Act provides that health care facilities that receive Medicaid or Medicare funds must provide written information at the time of admission about patients' rights under state law to make decisions about medical care, including the right to accept or reject medical treatment and to create advance directives); Colo. Rev. Stat. §§ 15-18-101 to 15-18-113 (1987 & Supp. 1996) (which provides for proxy decision-makers for medical treatment; N.Y. Pub. Health Law §§ 2980 to 2994 (McKinney 1994 & Supp. 1996) (which provides for health care agents and proxies).

nation's demographics, including the aging of the population[3] and ethnic and cultural shifts.

Current medical technology can prevent or cure many diseases and significantly improve the quality of life for those suffering from chronic disorders. However, the same technology is often used to distort and prolong the dying process. Problems raised by the misapplication of technology and its lack of accessibility are compounded by widespread public and professional confusion or ignorance about the provision of such care.

In addition, significant gaps exist in the available empirical evidence concerning physician-assisted suicide, and public debate is at a comparatively formative stage. Reasonable consensus on these complex issues is unlikely until knowledge is more complete and widespread. As with any emerging body of thought and practice, there is inherent instability which augurs both progress and risk.

Thus, it is vitally important to differentiate among knowledge about physician-assisted suicide and medical technology that is fact-based, the fundamental questions remaining unanswered and the implication of such uncertainties.

SUMMARY OF ARGUMENT

I.

THERE IS PUBLIC AND PROFESSIONAL CONFUSION ABOUT END-OF-LIFE LEGAL AND MEDICAL ISSUES

A. THERE IS MISINFORMATION AND MISUNDERSTANDING ABOUT LIFE-SUSTAINING TREATMENTS

[3]Lakshmipathi Chelluri et al., Intensive Care for Critically Ill Elderly: Mortality, Costs, and Quality of Life, 155 Archives Internal Med. 1013, 1013 (1995).

Patients frequently misunderstand the benefits and burdens of cardiopulmonary resuscitation, which has an extremely poor outcome in dying patients.[4] Research has demonstrated that when this is clarified, patients are far less likely to choose this life-sustaining intervention.[5]

Artificial nutrition and hydration are medical treatments that can be refused like any other treatments.[6] However, there is substantial misinformation and misunderstanding regarding these particular life-sustaining treatments.[7]

Both the Ninth Circuit in Compassion in Dying v. Washington,[8] ("Compassion"), and the Second Circuit in Quill v. Vacco,[8] ("Quill"), imply in their respective opinions that artificial nutrition and hydration are qualitatively different from other forms of life-sustaining treatment. Indeed, both courts use language about refusal of artificial nutrition that is often misconstrued, including the term "starvation."[9] In addition to being medically inaccurate, the term "starvation" is often emotion-laden and raises frightening images of hungry, otherwise healthy people who are prevented from obtaining desired

[4]Leslie J. Blackhall, Must We Always Use CPR?, 317 New Eng. J. Med. 1281, 1282-1283 (1987).

[5]Donald J. Murphy, et al., The Influence of the Probability of Survival on Patients' Preferences Regarding Cardiopulmonary Resuscitation, 330 New Eng. J. Med. 545, 546-547 (1994).

[6]Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, 278 (1990).

[7]Judith C. Ahronheim, Artificial Nutrition and Hydration in the Terminally Ill, 12 Clinics Geriatric Med. 379, 379-385, 387 (1996).

[8]Compassion In Dying v. Washington, 79 F.3d 790 (9th Cir. 1996), *cert. granted*, Washington v. Glucksberg, 65 U.S.L.W. 3254 (518 U.S. 1996) (no. 96-110); Quill v. Vacco, 80 F.3d 716 (2nd Cir. 1996), *cert. granted*, Vacco v. Quill, 65 U.S.L.W. 3254 (518 U.S. 1996) (No. 95-1858).

[9]Compassion, 79 F.3d at 822 (the court notes that states permit patients to discontinue artificial nutrition and hydration, "thus permitting the patients to die by self-starvation." The court also referred to Cruzan, where the removal of the feeding and hydration tube would allow her to "starve to death"); Quill, 80 F.3d at 729 (the court indicated that "the withdrawal of nutrition brings on death by starvation" and "the withdrawal of hydration brings on death by dehydration").

food.[10] The opinions further refer to forgoing artificial nutrition and hydration as "death by starvation," and "death by dehydration."[11] At the same time, the opinions fail to indicate that the nutritional deficiencies of starvation are insufficient to cause death early on.[12]

Artificial nutrition and hydration are medical treatments and should not be distinguished from other forms of life-sustaining treatment. The imposition of artificial nutrition and hydration may actually contribute to an uncomfortable death.[13] There is no evidence that individuals who are dependent upon artificial nutrition and hydration, whether alert and aware or with partial or severe neurological impairments, would experience any discomfort if these treatments were forgone. Indeed, extensive indirect evidence indicates that forgoing artificial nutrition and hydration facilitates natural death without discomfort.[14]

[10]Judith C. Ahronheim & M. Rose Gasner, The Sloganism of Starvation, 1 Lancet 278, 278 (1990).

[11]In Compassion, 79 F.3d at 822 (the court notes that states permit patients to discontinue artificial nutrition and hydration, "thus permitting the patients to die by self-starvation." The court also refers to Cruzan, where the removal of the feeding and hydration tube would allow her to "starve to death"); Quill, 80 F.3d at 729 (the court indicats that "the withdrawal of nutrition brings on death by starvation" and "the withdrawal of hydration brings on death by dehydration").

[12]Judith C. Ahronheim & M. Rose Gasner, The Sloganism of Starvation, 1 Lancet 278, 279 (1990).

[13]Judith C. Ahronheim, Artificial Nutrition and Hydration in the Terminally Ill, 12 Clinics Geriatric Med. 379, 380-381 (1996). (For example, enteral tube feeding [artificial nutrition and hydration via a tube placed into the stomach or small intestine] may produce a variety of uncomfortable symptoms and discontinuance may alleviate the discomfort.)

[14]Id. at 385.

Specifically, direct evidence indicates that competent hospice patients eat and drink little at the end of their lives and do not experience additional discomfort by avoiding artificial nutrition and hydration.[15]

The majority of case calls[16] regarding unwanted treatment received by Choice In Dying involve artificial nutrition and hydration.[17] These calls range from complex points of clarification to conflict resolution. This direct experience further highlights the misconceptions and continuing controversy surrounding this treatment.

Thus, despite the established constitutional right of the individual to forgo life-sustaining treatments, including artificial nutrition and hydration, ignorance of the law and misunderstanding about the treatments themselves indicates a far-reaching societal concern.

B. THERE ARE IMPORTANT DISTINCTIONS BETWEEN THE WITHHOLDING OR WITHDRAWAL OF LIFE-SUSTAINING TREATMENT AND PHYSICIAN-ASSISTED SUICIDE

The Second Circuit in Quill, supra, and the Ninth Circuit in Compassion, supra, confused the distinctions between physi-

[15]Robert M. McCann, et al., Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration, 272 JAMA 1263, 1264-1265 (1994).

[16]Choice In Dying provides a national hotline to respond to individual requests for counseling, consultation and crisis resolution ("case calls").

[17]66% of 600 calls received between January 1994 and July 1996.

[18]Quill, 80 F.3d at 727 (where the court held that those in the final stages of terminal illness who are on life-support systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated); Quill, 80 F.3d at 729 (where the court held that by withholding or withdrawing a patient "hastens his death by means that are not natural in any sense.")

cian-assisted suicide and the forgoing of life-sustaining treatment.

In Quill, the court repeatedly refers to termination of life support as the "hastening of death."[18] In Compassion, the court looks to the Cruzan case as a recognition that the termination of life-support is the hastening of death.[19]

The forgoing of life-sustaining treatment refers to the avoidance of a medical treatment that is necessary to sustain life. These treatments include cardiopulmonary resuscitation when heartbeat or breathing stops; mechanical ventilation when the patient can no longer breathe without artificial support; artificial nutrition and hydration when a person cannot eat or drink enough by mouth to sustain life; or a procedure to take the place of a malfunctioning vital organ, such as dialysis for failed
kidneys.[20]

These life-sustaining treatments artificially postpone natural death, and the withholding or withdrawing of these treatments removes the obstacle. The Ninth Circuit, when discussing Cruzan, noted that Nancy Cruzan lived with artificial nutrition and hydration for 8 years. A person in a persistent vegetative state[22] ("PVS") cannot live without artificial nutrition and hydration. The existence of individuals in PVS continues far beyond the time they would have died a natural death

[19]Compassion, 799 F.3d at 816 (the court viewed Cruzan as a case that hastened death: "...Cruzan, by recognizing a liberty interest that includes the refusal of artificial provision of life-sustaining food and water, necessarily recognizes a liberty interest in hastening one's own death.").

[20]When these treatments prolong life in someone with serious underlying illness, such as cancer or Alzheimer's disease, they will enable the patient to survive into a more advanced and debilitating stage of the disease.

[21]Cruzan v. Director, Missouri Dept. of Health, 497 U.S. 261 (1990).

[22]The Multi-Society Task Force on PVS, Am. Acad. of Neurology, No. 21, Pt. 1, Medical Aspects of the Persistent Vegetative State, 330 New Eng. J. Med. 1499-1502 (1994).

because of the artificial prolongation of life.

By contrast to the above, physician-assisted suicide is a specific intervention that actively hastens death. A failure to comply with a request to withhold or withdraw life-sustaining treat- ment would subject an individual to unwanted treatment and, as such, make him or her a virtual''prisoner of medical technology."[23] A failure to comply with a request for physician-assisted suicide would restrict patient autonomy, but would not amount to a bodily invasion.[24]

C. IN BOTH CASES UNDER REVIEW, THE SECOND AND NINTH CIRCUIT COURTS HAVE BLURRED THE DISTINCTION BETWEEN PHYSICIAN-ASSISTED SUICIDE AND THE POTENTIAL DOUBLE EFFECT OF PAIN MEDICATION IN CERTAIN CIRCUMSTANCES

The term "double effect" refers to the administration of pain medication with the intention of providing relief from suffering, with the possible secondary effect of hastening death. However, such hastening of death is theoretical.[25]

In the two cases under review, both courts have confused the distinction between physician-assisted suicide and double effect,[26] treating them as though they are equivalent. These

[23]Franklin G. Miller, Legalizing Physician-Assisted Suicide by Judicial Decision: A Critical Appraisal, 1, 10 (April 1996) (unpublished manuscript).

[24]Id. at 10.

[25]Compassion, 79 F.3d at 823 (the court, in discussing double effect, notes that the medication "will" cause death, although citing language from physicians that it "may" cause death).

[26]Compassion, 79 F.3d at 824 (the court notes that there was little or no difference "for constitutional or ethical purposes between providing medication with a double effect and providing medication with a single effect, as long as one of the known effects in each case is to hasten the end of the patient's life).

[27]David A. Asch, The Role of Critical Care Nurses in Euthanasia and

concepts also have been blurred by professionals, as witnessed in a recent study of intensive care nurses, some of whom considered administration of symptom-controlling medication to be the same as euthanasia.[27]

Among ethicists and within the law there is widespread consensus that the "double effect" is a morally acceptable risk in the context of the great suffering of the terminally ill.[28] By contrast, there is persistent controversy over the provision of medications in order to deliberately hasten death, as in physician-assisted suicide, regardless of the extent of the patient's suffering.[29]

The medications administered to relieve suffering may also lower blood pressure and depress respiration, and become "risky" in patients with low blood pressure or respiratory failure. However, it is not possible to prove whether the disease or the medication is responsible for the precise moment of death. A patient undergoing terminal respirator withdrawal, also known as "terminal weaning," is likely to have intense fear, anxiety and breathlessness unless precautions are taken, such as adjustment of the respirator settings or administration of sufficient sedation, for example, with morphine. Either method increases carbon dioxide levels in the blood, and produces respiratory failure. However, since withdrawal of the respirator with or without palliation will inevitably result in death, it is not possible to know if the morphine or the disease produced the actual moment of death.[30]

In contrast to the theoretical hastening of death in someone with low blood pressure or respiratory failure, the effect of a

Assisted Suicide, 334 New Eng. J. Med. 1374, 1376 (1996).

[28]The New York State Task Force on Life and the Law, When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context, 1, 163 (1994).

[29]Id. at 162.

[30]William C. Wilson, et al., Ordering and Administration of Sedatives and Analgesics During the Withholding and Withdrawal of Life Support

lethal dose of medication (either a known lethal dose in someone who has not developed tolerance to that medication, or an extremely large incremental dose in someone who already has been taking the medication) is predictable when it is given to someone who is not physiologically near death.

D. THERE IS A LACK OF CONSENSUS AS TO THE DEFINITIONS OF TERMINAL ILLNESS

In Quill, supra, the court indicated that physicians would agree on when the "final stages" of a "terminal illness" would occur,[31] and in Compassion, supra, the court stated that "[W]hile defining the term 'terminally ill' is not free from difficulty, the experience of the states has proved that the class of the terminally ill is neither indefinable nor undefined..."[32] Notwithstanding these opinions, Choice In Dying has often found profound disagreement among professionals and others concerning the definition of terminal illness.

Terminal illness has been variously defined by the states. New York has defined the term by applying a time of of one year.[33] New Jersey defines terminal condition as requiring a life expectancy of six months or less, with or without the provision of life-sustaining treatment."[34] Colorado defines terminal condition as one in which the administration of life-sustaining procedures will serve only to postpone the moment of death.[35]

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from Critically Ill Patients. 267 JAMA 949, 951-953 (1992).

[31]Quill , 80 F.3d at 731.

[32]Compassion, 79 F.3d at 831.

[33]N.Y. Pub. Health Law §2961(23) (McKinney 1996).

[34]N.J. Stat. Ann. §26:2H-55 (West 1995).

[35]Colo. Rev. Stat. §15-18-103(10) (1996).

[36]Cal. Health & Safety Code §7186(j) (West 1996).

[37]Ill. Comp. Stat. 110 1/2, §702(h) (West 1995).

[38]Mo. Ann. Stat. §459.010(6) (1992).

California defines terminal condition as a condition that results in death within a relatively short time without the administration of life-sustaining treatment[36] and Illinois as one in which death is imminent.[37] Lastly, Missouri requires that death will occur within a short time regardless of the application of medical procedures.[38]

Furthermore, it recently has been reported[39] that 14.9% of patients referred to hospice actually lived longer than 6 months, which is the maximum projected life expectancy that satisfies the hospice definition of "terminal illness." Additional studies have documented the uncertainties involved in predicting survival among patients with a variety of serious illnesses.[40]

The variety of existing definitions of "terminal illness" and the inability to accurately predict the time of death illustrates confusion, not clarity, regarding what constitutes terminal illness.

E. INDIVIDUALS' RIGHT TO FORGO TREATMENT IS POORLY UNDERSTOOD BY THE PUBLIC AND INSUFFICIENTLY HONORED BY PROVIDERS

Choice In Dying's experince over time illustrates that patients frequently receive unwanted medical treatments that prolong their lives, and conflict often continues to occur between

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[39]Nicholas A. Christakis & Jose J. Escarce, Survival of Medicare Patients After Enrollment in Hospice Programs, 335 New Eng. J. Med. 172, 174 (1996).

[40]David B. Reuben et al., Clinical Symptoms and Length of Survival in Patients with Terminal Cancer, 148 Archives Internal Med. 1586, 1588 (1988); Robert A. Pearlman, Variability in Physician Estimates of Survival in Acute Respiratory Failure in Chronic Obstructive Pulmonary Disease, 91 Chest 515, 516-517 (1987).

providers and patients.

Among 922 case calls received during a recent 30-month period, 65% involved concerns over unwanted treatments, and in 74% of these instances there was a dispute, usually between a patient or family member and the health care provider over the use of life-sustaining treatments.

In approximately 75% of case calls, the caller states that the patient in question has executed a formal advance directive. This rate is much higher than among the public at large (15%-25%) and even higher than selected groups with terminal illness (more than 50%).[41] Because patients with advance directives tend to be better educated and more affluent,[42] the problem of unwanted treatment may well be much broader demographically than is suggested by Choice In Dying's experience.

Furthermore, earlier published experience from Choice in Dying regarding conflicts over artificial nutrition and hydration illustrated that patients represented by case calls were much older and reflected a broader range of clinical situations than those represented by case law on which legal theory has been based.[43]

This organization's actual experience and the most recent studies on physician-patient communication and physician biases highlight the need for the courts to be thoroughly apprised of patient-based attitudes and experiences.

II.
PAIN AND OTHER PHYSICAL SYMPTOMS

[41]Steven H. Miles, et al., Advance End-of-Life Treatment Planning, 156 Archives Internal Med. 1062, 1063 (1996).

[42]Id. at 1063.

[43]Judith C. Ahronheim & Michael Mulvihill, Refusal of Tube Feeding as Seen From a Patient Advocacy Organization: A Comparison With Landmark Cases, 39 J. Am. Geriatric Soc'y 1124, 1125-6 (1991).

ASSOCIATED WITH TERMINAL ILLNESS ARE OFTEN NOT ADEQUATELY MANAGED

A. THERE IS OVERUSE OF POTENTIALLY PAINFUL LIFE-SUSTAINING TREATMENT IN DYING PATIENTS

Many terminally ill patients are overtreated with invasive and sometimes painful procedures and treatments that prolong their lives.

According to a recent multicenter study, death often is preceded by protracted hospital stays involving invasive treatments, with possibly 50% of patients dying in pain.[44] In one series of incurably ill hospitalized patients, one or more invasive nonpalliative treatments was instituted in 47% of the cases.[45]

Overtreatment of terminally ill patients with invasive and sometimes painful procedures may be, in part, the result of poor attention by physicians to patient preferences about certain end-of-life treatment decisions.[46] Physician biases are implicated as well, including a preference for withdrawing certain life-sustaining treatments over others, despite similar clinical circumstances.[47]

Poor communication between physicians and patients and physician's biases may have significant ramifications for pa-

[44]The SUPPORT Principal Investigators, A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), 274 JAMA 1591, 1594 (1995).

[45]Judith C. Ahronheim et al., Treatment of the Dying in the Acute-Care Hospital: Advanced Dementia and Metastatic Cancer, 56 Archives Internal Med. 2094, 2096 (1996).

[46]The SUPPORT Principal Investigators, at 1591, 1595.

[47]Nicholas A. Christakis & David A. Asch, Biases in How Physicians Choose to Withdraw Life Support, 342 Lancet 642, 643 (1993).

[48]Ivan Lichter & Esther Hunt, The Last 48 Hours of Life, 6 J. Palliative

tients in terms of personal autonomy and ultimately for appropriate palliative care. It is imperative that the court understand these dynamics as they bear upon the issue of physician-assisted suicide.

B. DATA SUGGEST THAT DYING WITHOUT LIFE SUPPORT CAN BE A PEACEFUL PROCESS

Severe discomfort is not invariably associated with the final stages of a terminal illness.[48]

Many people remain alert or semi-alert until the end, but many develop coma[49] prior to death. Coma has many causes but can stem from potentially reversible medical illness.[50] The treatment and reversal of medically induced coma can restore alertness without improving the prognosis of the underlying illness.

In dying patients, coma may act as a natural form of anesthesia so that the hours or days before death are devoid of pain, fear or suffering.[51] This disease-induced ("natural") condition resembles a drug-induced sleep similar to anesthesia. Avoiding treatment that would revers coma allows death to occur naturally and peacefully.

C. TECHNOLOGY IS AVAILABLE FOR MANAGING

Care 7 (1990).

[49]Fred Plum & Jerome B. Posner, The Diagnosis of Stupor and Coma, No. 19, at 5 (Fred Plum & Fletcher H. McDowell, eds., 3rd ed., 1980). (Coma is an unarousable sleep-like state in which a person demonstrates no ability to experience pleasure, pain or suffering.)

[50]Id. at 177-180.

[51]Judith Ahronheim & Doron Weber, Final Passages: Positive Choices For the Dying and TheirLoved Ones, 160-179 (Fred Hills, ed., Simon & Schuster 1992).

[52]Detlev FJ Zech, et al., Validation of World Health Organization Guidelines for Cancer Pain Relief: A 10-year Prospective Study, 63 Pain 65, 73 (1995).

PAIN AND OTHER SYMPTOMS ASSOCIATED WITH TERMINAL ILLNESS

Pain and other physical symptoms can be appropriately controlled, in the vast majority of cases, within the confines of standard medical practice.

In approximately 90% of cancer patients, pain can be adequately controlled when standard, accepted measures are used.[52] Although potent medications sometimes can reduce alertness, psychostimulant medications are available that can ameliorate that problem.[53] Furthermore, a variety of management techniques are available that can ameliorate other physical symptoms associated with terminal illness, such as vomiting and breathing difficulties.[54] These approaches, along with a large and evolving body of knowledge, are embodied in the discipline of "palliative medicine."[55]

Despite the advances that have been made in symptom control, physical symptoms remain uncontrolled in some individu-

[53]Nathan I. Cherney & Kathleen M. Foley, Nonopioid and Opioid Analgesic Pharmacotherapy of Cancer Pain, 10 Hematology/Oncology Clinics N. Am. 79, 94 (1996).

[54]Lichter & Hunt, supra, at 8, 8-13.

[55]Oxford Textbook of Palliative Medicine, Derek Doyle, et al., (eds)., (1993).

[56]William R. Greene & William H. Davis, Titrated Intravenous Barbiturates in the Control of Symptoms in Patients with Terminal Cancer, 84 S. Med. J 332, 332-335 (1991).

[57]Susan D. Block & J. Andrew Billings, Patient Requests to Hasten Death, 154 Archives Internal Med. 2039, 2040 (1994). (Block and Billings have stated that "euthanasia and assisted suicide may... become irrelevant.").

[58]Daniel N. Levin, et al., Public Attitudes Toward Cancer Pain, 42 Cancer 1385 (1985).

[59]Kathleen M. Foley, The Relationship of Pain and Symptom Management to Patient Requests For Physician-Assisted Suicide, 6 J. Pain

als and relief will not be adequate unless these patients receive treatment that will suppress consciousness.[56] Although commentators have noted that patients are likely to feel reassured that this option is available,[57] some patients wish to remain alert, and would find suicide preferable to suppression of consciousness.

Although fear of unremitting pain is an important public concern that could increase the resort to assisted suicide in some individuals,[58] adequate control of pain and physical symptoms may lead to a decrease in requests for suicide.[59] In one series, only one half of one percent of hospice patients persistent requests to hasten death,[60] suggesting that in supportive settings, where pain is well managed, a reduction in suicide requests would occur.

A critical dichotomy exists between pain or other physical symptoms and the phenomenon termed "suffering." Suffering is a highly subjective, individual experience, which may, but does not always, evolve from pain or other physical symptoms.[61]

Moreover, psychiatric illness or other psychosocial factors,

& Symptom Mgmt 289, 290 (1991).

[60]Block & Billings, supra, at 2040 (1994).

[61]Eric J. Cassel, The Nature of Suffering and the Goals of Medicine, (1991).

[62]Ezekiel J. Emanuel, Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences of Oncology Patients, Oncologists, and the Public, 347 Lancet 1805, 1809 (1996); Harvey Max Chochinov et al., Desire for Death in the Terminally Ill, 152 Am. J. Psychiatry 1185, 1188 (1995); William Breitbart et al., Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients, 153 Am. J. Psychiatry 238, 240 (1996).

[63]William Breitbart, Psychiatric Management of Cancer Pain, 63 Cancer 2336, 2337 (1989).

[64]Id. at 2337.

[65]William Breitbart et al., Psychiatric Aspects of Palliative Care, Oxford Textbook of Palliative Med. 613 (Derek Doyle et al. eds., 1993).

even more than intolerable physical symptoms, may increase interest in physician-assisted suicide, or may increase the desire to die among the terminally ill.[62] Psychiatric illness may also be the primary cause of unremitting suffering.

Psychiatric disorders, especially depression, increase the risk of suicide among the terminally ill.[63] In addition, disease or drug-induced delirium also may increase the risk.[64] Although the desire for death in terminally ill patients is closely associated with clinical depression, even depression associated with dying can be treated adequately.[65]

Finally, discussion regarding unremitting pain and symptoms must include those individuals with chronic illnesses who are not "terminally ill," including patients with diseases such as multiple sclerosis, stroke, Alzheimer's disease or severe autoimmune disease. Any ruling on the narrow question before this Court may not necessarily address the intractable and intolerable suffering of those who do not have a medical illness or whose condition has not been defined as "terminal."

D. STATE-OF-THE ART CARE FOR SYMPTOMS ASSOCIATED WITH TERMINAL ILLNESS IS NOT ROUTINELY PROVIDED

Studies have indicated that pain is undertreated in people with serious illnesses,[66] despite the availability of appropriate treatments. Although the means exist to address and alleviate psychiatric illness in incurable disease, little empirical evi-

[66]William Breitbart et al., The Undertreatment of Pain in Ambulatory AIDS Patients, 65 Pain 243, 247 (1996); Charles S. Cleeland et al., Pain and Its Treatment in Outpatients with Metastatic Cancer, 330 New Eng. J. Med. 592, 593-594 (1994).

[67]Jamie H. Von Roenn et al., Physician Attitudes and Practice in Cancer Pain Management: A Survey From the Eastern Cooperative Oncology Group, 119 Annals Internal Med. 121 (1993); Kathleen M. Foley, The Relationship of Pain and Symptom Management to Patient Requests For

dence exists about the extent to which management of these symptoms is practiced.

There are remediable reasons for the undertreatment of pain and suffering associated with terminal illness, including, but not limited to, a lack of third-party insurance coverage, a lack of professional education, unwarranted fears of addiction and concerns regarding legal restrictions in the use of controlled substances.[67]

Access to effective palliative care may be limited. The lack of access is due in part to the limited number of sites where this care is provided and to lack of adequate third-party insurance coverage.

Estimates are that the 2,000 certified hospices in the United States are involved in managing fewer than 15% of deaths.[68] In addition, these programs are largely home-based, requiring able-bodied caregivers in the home, a criterion not always met in today's society. Medicare does provide coverage for hospice care, but the availability of the benefit and mechanics of electing it are often poorly understood by beneficiaries. Similarly, there is lack of awareness and understanding of hospice benefits under private plans because this coverage also is a fairly new addition to many policies.

Only recently the Health Care Financing Administration began to study reimbursement of palliative or terminal care in the acute care setting.[69] Such coverage would address a critical need because approximately 60% of adult Americans currently die as inpatients in acute-care hospitals.[70]

E. PUBLIC MISCONCEPTIONS ABOUT MANAGE-

Physician-Assisted Suicide, 6 J Pain & Symptom Mgmt 289 (1991).

[68]Hospice Fact Sheet, (National Hospice Organization), July 1, 1996.

[69]Christine K. Cassel & Bruce C. Vladek, ICD-9 Code for Palliative or Terminal Care, 335 New Eng. J. Med. 1232, 1232 (1996).

MENT OF PAIN AND SUFFERING DISTORT DEBATE ABOUT PHYSICIAN-ASSISTED SUICIDE

Most individuals with terminal illness do not have to experience undue suffering. However, pain and physical symptoms are primary concerns patients have about dying, even though medical technology is available to relieve severe pain and other physical symptoms. In Compassion, supra, the court reflected the prevailing feeling that extreme pain and physical symptoms are inevitably associated with terminal illness.[71] Public education is critical to dispelling this misconception and enhanced professional education is necessary to ensure that competent pain management is among accessible end-of-life care options.

III.
THE NATIONAL CONTROVERSY CONCERNING PHYSICIAN-ASSISTED SUICIDE IS RELATED TO SERIOUS GAPS IN EMPIRICAL DATA

EMPIRICAL DATA ABOUT PHYSICIAN ATTITUDES AND PRACTICES CONCERNING PHYSICIAN-ASSISTED SUICIDE IS LIMITED

A.

The surveys concerning physicians' attitudes toward participating in hastening patients' death and their actual practices vary considerably in the specificity of the questions, the characteristics of the physicians surveyed, the response rates, the results and the methodologic quality. In

[70]National Center for Health Statistics, U.S. Dep't of Health and Hum Services, Vol. II- Mortality, Pt.A, Vital Statistics of the United States, 380, 381 (1993).

[71]Compassion, 79 F.3d at 812 ("Americans are living longer, and when they finally succumb to illness, lingering longer, either in great pain or in a stuporous, semi-comatose condition that results from the infusion of vast amounts of pain killing medications.").

terms of their generalizability to the country overall, most of the studies have inherent limitations and/or serious methodologic flaws.

In general, response rates in these surveys have increased over the years apparently since the debate has become more public and physicians less concerned about responding to questions in this area.[72]

B. EMPIRICAL DATA ABOUT PATIENT ATTITUDES AND PRACTICES CONCERNING PHYSICIAN-ASSISTED SUICIDE ARE LIMITED

Although studies indicate that the desire for death is not uncommon among terminally ill patients,[73] there has been little study of patients who actually request assistance from their physicians in hastening their death. The limited data available are based primarily on reports from physicians.[74]

Approximately 11% of Choice In Dying case calls are inquiries about assisted dying. Among 95 recent cases, fewer than half were calling on their own behalf; 59 (63%) were inquiring about assistance for others, usually family members or close friends. Among the group for whom family or close friends were seeking assistance, only 31 reportedly were able to communicate their wishes, 17 could not do so, the capacity of 9 was uncertain, and 2 had psychiatric disease rather than medical illness. Although most calls involved people with terminal illness, including cancer and AIDS, 8 had chronic medical illness, 10 had dementia, 5 had strokes, 3 had prolonged unconsciousness and 3 had other severe neurological impairments. Two calls involved impaired newborns. None of these calls involved inquiries about withholding or withdrawing life support.

Thus, Choice In Dying's experience is consistent with the notion that societal concerns about aid in dying are very broadly based. Concerns extend not only to an array of illnesses but also to patients with limited or lack of capacity.

[72]A significant amount of the data came from Washington and Oregon, where physician-assisted suicide has been the subject of public referenda.

[73]Chochinov et al., supra (44.5% of terminally ill hospice patients indicated that they had occasional desires for death.)

[74]Paul J. van der Maas et al., Euthanasia and Other Medical Decisions Concerning the End of Life, 338 Lancet 669, 670 (1991); Anthony L. Back et al., Physician-Assisted Suicide and Euthanasia in Washington state, 275 JAMA 919, 922 (1996).

IV. CONCLUSION

Choice In Dying takes no position with respect to the holdings in the two cases before the Court, nor with respect to the legality or constitutionality of physician-assisted suicide. However, when this Court decides these cases and the important constitutional issues that underlie them, we respectfully ask that it consider the data we have presented in this submission. From such data, we respectfully submit the following conclusions should be drawn:

- There is a crucial distinction between a patient's decision to forgo medical treatment at the end of life and his decision to seek the assistance of a physician in committing suicide.
- There is no public or professional consensus by which "terminal illness" may be defined, nor does the term even encompass many individuals who are not "terminally ill" who seek to forgo life-sustaining treatments, These distinctions are central to any thorough analysis of physician--assisted suicide.

Contrary to public and judicial opinion, there is effective technology available for managing pain and other symptoms associated with terminal illness. There no longer is any technologic reason for most people to die in agony.

- There is preliminary evidence that when pain and other symptoms of terminal illness are managed effectively, desire and requests for physician-assisted suicide are reduced.

- There is evidence that potentially painful life-sustaining treatments are vastly overused among dying patients, and that withdrawing these treatments properly in individuals close to death causes little or no discomfort.

- Contrary to some public and professional opinion, forgoing artificial nutrition and hydration contributes to comfort in dying patients.

- Cardiopulmonary resuscitation has negligible or no benefit in individuals close to death and frequently is refused when patients and their families are informed of the burdens and lack of benefit associated with this life-sustaining treatment.

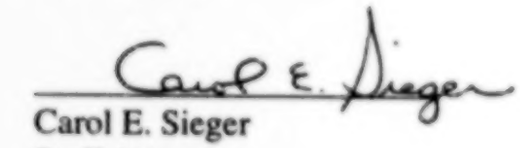
- Treating pain and other symptoms associated with terminal illness and withholding or withdrawing life sustaining treatments permits a natural death to occur. The process of natural death can be pain-free in many cases.

- Despite technologic capacity, palliative care is not widely provided and there is limited third-party coverage for such services.

- Evidence from Choice In Dying's direct contact with patients and providers indicates that many patients still receive unwanted treatment, and that unwanted treatment, as a concern, may far outweigh desire for assisted suicide among the dying.

We respectfully submit that the opinions under review do not adequately consider the factors enumerated above. Indeed, both Quill and Compassion rely significantly upon some of the serious misconceptions that we have sought to clarify in this submission. We respectfully ask the Court, in resolving the important issues at bar, to consider the data we have presented and the important conclusions drawn therefrom.

Respectfully Submitted,



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